

Caregiver burden and the role of social support in the care of children with cystic fibrosis

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A – Study Design, **B** – Data Collection, **C** – Statistical Analysis, **D** – Data Interpretation, **E** – Manuscript Preparation, **F** – Literature Search, **G** – Funds Collection

Summary Background. The effort involved in caring for a patient suffering from cystic fibrosis lies with its parents/caregiver, becoming the cause of excessive burden. In such a situation, social support is an important strategy for coping with chronic illnesses.

Objectives. The aim of the study was to assess the level of burden and social support for parents of children with CF and to establish a relationship between them.

Material and methods. The study involved 88 parents of patients with cystic fibrosis. The study utilized the standardized *Caregiver Burden Scale* (CB) and the *Berlin Social Support Scale* (BSSS).

Results. The study group experienced an average burden level, which is dependent on the level of education. The highest level of burden was found in two subscales: *disappointment* and *general effort*, and the lowest was in the *emotional involvement* subscale. The level of support in the studied group was high. The largest was observed in the subscale *perceived support* and *received support*, and the lowest in the subscale *seeking support*. Analysis of the regression of the dependent variable of the caregiver's level of burden showed that the level of burden determines the need for support. It has been observed that as the level of the caregiver's burden increases, the need for support also increases. In turn, the smaller the caregiver's burden, the lower the need for support currently received.

Conclusions. The caregiver burden on the parent of a children suffering from CF and the received social support are important factors influencing each other in the care of a chronically ill child. This means that the more support received, the lower the sense of burden the caregiver experiences.

Key words: cystic fibrosis, caregivers, parents, social support.

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Background

Treatment of cystic fibrosis (CF) is comprehensive and multidisciplinary. It includes prophylaxis and treatment of the broncho-pulmonary disease, therapy of pancreatic insufficiency and treatment of complications and co-morbidities [1]. There is no doubt that the specific nature of this disease requires ceaseless prevention of its development, constant struggle and painstaking routine activities without any visible effects. However, thanks to the perseverance and effort of parents, these allow for the prolongation of children's lives and improve their mental and physical condition [2]. As a result of long-term care, the parents/caregivers experience resignation, a sense of loneliness, loss of valuable interpersonal contacts, lack of interests, dissatisfaction with their own life situation and sometimes even negative feelings towards the child [2–4]. This causes stress, which leads to physical, emotional, mental, social and financial depletion [4–7]. The burden can be discussed in relation to objective and subjective aspects [5, 6]. Objective or measurable indicators in the caregiver's functioning include time and physical effort, chronicity and severity of symptoms, as well as socio-demographic indicators, i.e. gender, education level and earnings. The subjective approach to burden refers to physical and mental suffering, as well as emotional and social experiences arising as a result of the child's illness. It is difficult to verify this type of burden, because it is related to the caregiver's individual ways of coping, as well as the level of social support received [8, 9]. Support is a protective factor in the struggle and in overcoming a difficult situation [8, 10]. Researchers also increasingly often reject the concept of burden with care, replacing it with

“caregiving experience” or “caregiving consequences”, presenting the possible positive aspects of care [11].

Social support includes the resources and assistance that other people provide. It is a multidimensional concept that can be considered in structural and functional terms. The structural ones are actual ties and contacts, i.e. social networks to help people in a difficult situation. There are three categories of support sources: personal – these are family, friends and acquaintances or neighbors; formal – these are charities, social welfare and church communities; and professional sources – specialist clinics and support groups [8–10]. Functional support, on the other hand, is a social interaction taking place in a problem and stress situation. The types of support most often distinguished by researchers and theoreticians are: instrumental, informational, emotional, assessment, material (factual), evaluative, spiritual, integrating.

Objectives

The aim of the study was:

- 1) to assess the degree of caregiver burden and level of social support of parents of CF patients;
- 2) establish the relationship between socio-demographic variables, caregiver burden, as well as experience of social support.

Material and methods

The study was conducted between November 2015 and February 2016 in a group of parents of children suffering from



cystic fibrosis. The study was approved by the Bioethical Commission of the Andrzej Frycz Modrzewski Krakow University, dated November 19, 2015, opinion No. KBKA/44/O/2015.

The study group consisted of 88 parents ($M = 11.36\%$ ($n = 10$), $F = 88.64\%$ ($n = 78$)) of patients suffering from cystic fibrosis. The average age of the respondents was 39 ± 7.19 years. The most numerous groups were those aged 35–45 (46%, $n = 40$) and those aged 20–35 (37%, $n = 32$). The smallest group among the respondents was people over 45 (17%, $n = 15$). Almost half of respondents ($n = 41$, 46.6%) had secondary education, and 37 people (42%) had higher education. The least numerous group of respondents ($n = 10$, 11.4%) was people with basic and vocational education. Country dwellers accounted for 47% ($n = 41$) of respondents, and city dwellers for 53% ($n = 47$).

The vast majority (84%, $n = 74$) of the respondents were complete families. 36% ($n = 31$) of parents have one child; the more numerous group was parents with two children (39%, $n = 34$). Parents of four children accounted for 8% ($n = 7$). In contrast, 12 parents (13.7%) took care of two children with cystic fibrosis. Of all the parents surveyed, 70% ($n = 62$) declared that the child's illness influenced their possibility of performing work. 31.8% ($n = 28$) use social support. One-third of respondents took care of a sick child by themselves, and 58 people (66%) answered that they could rely on the support of family members or strangers. Approximately 80% ($n = 70$) of respondents used help or were involved in self-help associations/organizations (Table 1). The mean age of children with CF was 10 years, from 1 to 22 years old (± 6).

	<i>n</i>	%
Gender		
Female	78	88.6
Male	10	11.4
Age		
20–35 years	32	36.4
35–45 years	40	45.5
Above 45 years	16	18.1
Education		
Primary and vocational	10	11.4
Secondary	41	46.6
Bachelor's and Master's degrees	37	42.1
Place of residence		
Village	41	46.6
City up to 100,000 residents	28	31.8
City over 100,000 residents	19	21.6
Family structure		
Complete family	74	84.1
Single-parent family	14	15.9
Family economic situation		
Poor, average	49	55.7
Good, very good	39	44.3
Employment status		
Full-time job	24	27.3
Part-time job	12	13.6
Unemployed	24	27.3
Use of social support	28	31.8
Involvement in self-help associations/organizations	70	79.5

Methods

The study involved the diagnostic survey method. Polish versions of self-report tools with proven and good psychometric properties were used: *Caregiver Burden Scale* (CB Scale) [11] and the *Berlin Social Support Scale* (BSSS) [8, 10].

The *Caregiver Burden Scale* includes 22 questions in 5 subscales: General strain, Social isolation, Disappointment, Emo-

tional involvement and Environment. Answers are provided on a 4-point estimate scale. The Total Score for the CB Scale and the 5 subscales is the average score in individual items included in the scale (1 point – 4 points). The obtained results indicate the following burden categories: low level (1.00–1.99), medium level (2.00–2.99), high level (3.0–4.0). A higher number of points means a higher level of burden. A reliability index was calculated for the studied population, which was $\alpha = 0.76$. The authors of the Polish version agreed to use it in this research [11].

Berlin Social Support Scale (BSSS)

The *Berlin Social Support Scale* originally contained 6 independent subscales. For research purposes, 31 questions were in 4 subscales: Perceived support, Demand for support, Received support and Seeking support. Answers are provided on a 4-point estimate scale. A higher number of points means more social support. A reliability index was calculated for the studied population, which was $\alpha = 0.73$. The tool is “public domain”, and the authors of the Polish version agreed to use it in this research and analyzed only 4 subscales [8, 10].

Statistical analysis

Statistical analysis of the collected research material involved the StatSoft's statistical package Statistica v. 7.1, as well as Microsoft Excel 2000 and Microsoft Excel 2007. Statistical description methods were used in the presentation of the characteristics of the set of measurements for the examined feature (variable): location measure – arithmetic mean, median m and measures of differentiation – standard deviation (referred to as sd herein), minimum value (min, first quartile) and maximum (max, fourth quartile) of a given trait, as well as second and third quartile. The range of variability (min–max) of the characteristics studied in the paper was marked as scope.

The distribution normality of the variable was verified using the Shapiro–Wilk test. For variables that did not have a normal distribution, logarithmic transformations were used (e.g. variable: age). In the event that the above transformation provided no improvement in the normality of the distribution, non-parametric tests were used.

Statistical inference was performed using the following tests: Friedman's ANOVA test, Spearman's test and multiple regression analysis. Statistically significant results were those with a significance level lower than 0.05.

Results

The respondents rated their current state of health at 7.22 (SD 1.98) points on a 10-point scale (min 1, max 10). In the parents' opinion, the health condition of their children in the last year was stable in most cases (62%, $n = 55$). Regarding the frequency of stays with the child in the hospital, 60% ($n = 53$) of the respondents indicated such need once a year, 27% ($n = 24$) indicated 2–3 times a year, and 8% ($n = 7$) of parents must take the child to the hospital more than 3 times a year.

The Total score of the caregivers' burden in the *Caregiver Burden Scale* (CB Scale) was ($x = 2.47 \pm 0.47$). This indicates the average level of burden in the study group, which concerns 72.73% ($n = 63$) of respondents. For individual subscales, the mean burden values were within the average level, except for the “emotional involvement” subscale, the mean of which ($x = 1.96 \pm 0.66$) indicates a low level of burden. There were statistically significant differences between individual burden subscales ($p < 0.05$).

The percentage of people with an average level of burden for Total score and individual subscales of CB was the highest 56.82% ($n = 50$) for *general effort*, 50% (44) for *disappointment* and *environment*, and 48.86% ($n = 43$) for *emotional involvement*, respectively). The highest percentage of people in the

Caregiver Burden Subscales	Min	Max	Mean	SD	Level of burden (%)		
					Low	Average	High
Total score	1	4	2.47	0.47	13.64	72.73	13.64
General strain	1	4	2.67	0.56	12.50	56.82	30.68
Isolation	1	4	2.32	0.79	32.95	37.50	29.50
Disappointment	1	4	2.74	0.57	7.95	50.00	42.04
Emotional involvement	1	4	1.96	0.66	40.91	48.86	10.23
Environment	1	4	2.06	0.63	38.64	50.00	11.36

Abbreviations: min – minimum, max – maximum, SD – standard deviation.

Variable		Total score				F	p
		No.	Total score (Mean)	Total score SD	Degrees of freedom		
Education	Primary and vocational	10	2.20	0.42	2	5.49	0.005
	Secondary	41	2.38	0.43			
	Higher	37	2.65	0.47			

Abbreviations: No. – number of subjects, SD – standard deviation, F – test F, p – significance.

Subscales	Min	Max	Mean	SD	Level of support (%)		
					Low	Average	High
Perceived support	1	4	3.32	0.62	5.68%	15.91%	78.41%
Demand for support	1	4	3.07	0.64	4.54%	29.54%	65.91%
Received support	1	4	3.24	0.68	5.68%	26.14%	68.18%
Seeking support	1	4	2.79	0.77	11.36%	40.91%	47.73%
Total support	1	4	3.18	0.53	2.27%	32.95%	64.77%

Abbreviations: min – minimum, max – maximum, SD – standard deviation.

Pair of variables	Spearman's rank order correlation			
	No.	R Spearman	t(n - 2)	p
Support & Total score CB	88	-0.28	-2.68	0.009
Support currently received & Total score CB	88	-0.16	-1.98	0.04

Abbreviations: R Spearman – Spearman correlation, p – significance.

high burden category concerned *disappointment* and *general effort* (with 42.04% ($n = 37$) and 30.64% ($n = 25$), respectively). As far as the *social isolation* subscale was concerned, the percentage of responses was similar on each of the burden levels (low, medium and high). Therefore, *disappointment* and *general effort* were considered the most burdensome, while *emotional involvement* and *environment* – the least burdensome in the group of respondents (Table 2).

The dependence between the caregiver's burden and the following variables was analyzed: age, gender, education, place of residence, family structure, economic situation, the child's and the caregiver's health status, age of the sick child and degree of involvement in cooperation with associations/organizations supporting families of CF patients.

Among the mentioned variables, the only statistically significant variable was the relationship between education and the degree of burden. The one-way ANOVA analysis (analysis of variance) was used to examine the dependence between education and the general care burden. The average level of burden between caregivers belonging to three groups broken down by the level of education was compared. The obtained results showed a statistically significant difference in the mean

level of Total score between caregivers in relation to the level of education: $F_{2,85} = 5.49$, $p = 0.006$. The highest level of *general burden* was noted in the group of people with higher education, and the lowest in the group of people with basic and vocational education. The data acquired showed that the higher the level of the caregiver's education, the greater their sense of burden (Table 3).

Analyzing the support experience of the study group, a high level of support was noted for the majority of the group (64.44%, $n = 56$) – the *general support level* result measured by the BSSS scale was $x = 3.18 \pm 0.53$. The highest level of support was noted in the subscales *support available* ($x = 3.32 \pm 0.62$) and *support received* ($x = 3.24 \pm 0.68$). A high result was also observed in the *demand for support* subscale ($x = 3.07 \pm 0.64$). The lowest level of support was noted in the *seeking support* subscale ($x = 2.79 \pm 0.77$) (Table 4).

The Spearman's rank correlation coefficient was utilized in studying the dependence between the level of the caregiver's *general support* and *general burden* (Total score). The result obtained were statistically significant (R Spearman = -0.28, $p = 0.009$). This means that the caregiver's burden is correlated

with the experience of support. A statically significant dependence was also found between the support currently received and the general burden (Total score) ($r = -0.16, p < 0.05$) (Table 5).

As a result of the conducted analyzes, a statistically significant negative correlation was found between the caregiver's burden in the social support subscale and the general support subscale: general support ($r = -0.23, p < 0.05$), support available ($r = -0.20, p < 0.05$), seeking support ($r = -0.23, p < 0.05$). There was also a negative correlation between the support received and the level of general caregiver's burden and its subscales (Total score CB $r = -0.16$, social isolation $r = -0.25$, disappointment $r = -0.25$, emotional involvement $r = -0.16$, environment $r = 0.19, p < 0.05$).

Analysis of the regression of the dependent variable of the caregiver's level of burden showed that the demand for support and support currently received explain the dependent variable in 12% of cases ($R = 0.35 R^2 = 0.12 F(2.85) = 6.2371, p < 0.003$). In the case of demand for support, the higher the caregiver's burden, the greater the demand for support ($\beta = 0.28$). In the case of currently received support, the smaller the caregiver's burden, the lower the need for currently received support ($\beta = -0.32$).

Discussion

The aim of the conducted research among 88 parents of patients suffering from cystic fibrosis was to determine the level of burden and the degree of social support obtained by the caregiver of a chronically ill child, as well as to determine the relationship between socio-demographic variables, the parent's health, the caregiver burden, as well as social support experienced.

Treatment of cystic fibrosis takes place primarily in the child's home. The effort of care rests with parents mainly in applying a diet, supply of pancreatic enzymes, vitamins, antibiotics, mucolytics and daily rehabilitation of the respiratory system (inhalation, drainage, physiotherapy). This results not only in the high costs of the treatment itself, but also places a financial burden on parents who give up their professional lives to look after their sick child at home [12]. Parents bear the responsibility for the state of treatment and the child's improvement, and the care requirements also increase as the disease progresses. Uncertainty about the future is becoming a serious issue [13].

An analysis of literature suggests that the stress experienced by the caregivers of chronically ill children leads to the conclusion that this group shows a significantly higher level of stress compared to the caregivers of healthy children. This stress lies at the root of neurotic and depressive disorders, or the breakdown of family or marital relationships [14].

In an own study, it was shown that education and the associated greater awareness, together with the need to acquire knowledge of both the disease and its effects, may be the cause of a greater sense of burden. The education level in the study group may also be related to the position held, the type of work performed and the responsibility for it, which is associated with greater stress and workload and may affect parental responsibilities.

Further analysis showed that despite the fact that the majority of respondents ($n = 49$) assessed it as poor and average, the economic situation did not have a significant impact on the level of general burden. This result is surprising, as in an own study, 70% of respondents declared that the disease affects their work performance, with 40.9% working, 13.6% of which work part-time, and one-third of parents declared that they benefit from social support. Similarly, in a study by Neri et al. [15], it was shown that the parents of young CF patients ($x = 16 \pm 2.6$) declared a lower socio-economic status, giving up their professional work. A higher percentage of parents taking up employment compared to own research (54.4%).

The above data would suggest that the burden of caring for a chronically ill child should correlate with one's economic situation. However, in an own study, the socio-economic status was not analyzed using an objective indicator, i.e. the income obtained. Therefore, it is difficult to compare with data from literature, where there is evidence that the socio-economic status (SES) of CF patients plays an important role as a factor modifying the course of the disease and prognosis [16]. Studies by Sahni et al. showed that a lower SES, measured on the basis of average income and type of health insurance, is an independent risk factor for death in the CF population [16].

On the other hand, failure to show the dependence between the socio-economic status and the caregiver's burden in the study may result from the fact that in 36% of cases, the child suffering from CF is the only child in the family. Caring for a single child is less financially burdensome than caring for large families. It also seems that the role of support and the ability to rely on the help of others is an important factor that helps parents cope with the child's illness. Majority of the surveyed group (over 80%) were complete families benefiting from the help of self-help associations/organizations. Undoubtedly, the psychological, information and instructional support provided by these associations/organizations is a huge help for parents and a factor that reduces the perceived level of burden. They also provide an opportunity to contact parents with similar problems and exchange experiences.

The average level of burden in the study group may result from the fact that the parents assessed the health of children as good, and the result of this assessment was: $x = 7.22 \pm 1.98$ (on a scale from 0 to 10). This means that a large group of children enjoys good health in the opinion of parents, so the burden on the parent is not high. This condition can be explained by the low average age of the respondents' children ($x = 10.4 \pm 6.4$ years). This was confirmed in a study by Fitzgerald et al. [17], which showed that the older the CF patients, the higher the burden level. In the same study, the second factor associated with the higher burden level was *Pseudomonas aureginosa* infection, which indicates disease progression. This thesis was confirmed by Wojtaszczyk et al. [18] in their work assessing the burden of caregivers of adult patients with CF, where it was shown that along with the deterioration of health, the caregivers experienced more stress.

Studying the dependence between the level of general support assessed according to the BSSS scale and the caregiver general burden scale (CBS), a significant negative correlation of these two variables was noticed. This means that the more support received, the lower the sense of burden the caregiver experiences. Similar results were found in a study by Parchoimiuk [19], in which, using the same tools (CBS) and (BSSS), it was shown that mothers of children with intellectual disability experience more burden and seek more social support than mothers of healthy children. Moreover, the analyzed literature confirms that mothers of sick children show high levels of stress, and even depressive disorders [15, 19].

Wong and Heriot [20] described the parent's attitude towards the child and their illness. It has a huge impact on coping with the child's disease. The authors note two approaches among parents, calling them substitute hope and despair. These two approaches determine the manner of adapting to living with the disease. In one case, anxiety, depression, loss of motivation increase, and in the other, emotional support and hope give strength, reduce the level of anxiety and suffering. Research confirms that the parents' attitude has a significant impact on the attitude of children. According to the authors, strengthening the parents' substitute hope improves the mental condition of sick children [20].

One should not overlook the positive features of caring for a sick family member, which are very individual and may change over time. These are a greater sense of satisfaction and personal reward from care. Challenges associated with the struggle

with the disease become a source of experience and thus allow for a more mature assessment of the world, greater ability to empathize and can also be a factor in improving relationships with others or changing one's system of values [21]. Therefore, healthcare providers should regularly pay attention to family caregivers, regardless of the patient's condition and age.

This study contributes new findings to the sparse literature on caregiver burden of parents of young children with CF. Caregiving burden is a relevant and frequent issue among parents of adolescent patients with cystic fibrosis.

Limitations of the study

The main limitation of this study was the small size of the study group. This is why our findings may not be internationally generalizable.

Implications for clinical practice

1. The burden on the parent of a child suffering from cystic fibrosis determines the social support received.

2. Healthcare providers should regularly pay attention to family caregivers, regardless of the patient's condition and age.

Conclusions

1. The burden on the parent of a child suffering from CF was at an average level and was dependent on the level of education. The most burdensome factors proved to be disappointment and the effort put into care.
2. The burden on the parent of a child suffering from cystic fibrosis determined the social support received. As the level of the caregiver's burden increased, the need for support also increased. In turn, the less the caregiver's burden, the lower the need for support currently received.
3. The level of burden was dependent on education and determined the need for social support.

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Conflicts of interest: The authors declare no conflicts of interest.

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